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# Health Information Counselors: A New Profession for the Age of Big Data

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## Abstract

Health care is increasingly data driven. Concurrently, there are concerns that health professionals lack the time and training to guide patients through the growing medical “data jungle.” In the age of big data, ever wider domains of people’s lives are “datafied,” which renders ever more information—at least in principle—usable for health care purposes. Turning data into meaningful information for clinical practice—and deciding what data or information should not be used for this purpose—requires a significant amount of time, resources, and skill.

The authors argue that academic medicine should lead the way in navigating the use of complex, highly personal data in clinical practice. To make data actionable for both clinicians and patients, the authors propose that the best way to navigate the interface between patients and providers in the era of data-rich medicine would be the creation of a new profession entirely: health information counselors (HICs). HICs would have broad knowledge of various kinds of health data and data quality evaluation techniques, as

well as analytic skills in statistics and data interpretation. Trained also in interpersonal communication, health management, insurance systems, and medico-legal aspects of data privacy, HICs would know enough about clinical medicine to advise on the relevance of any kind of data for prevention, diagnosis, and treatment. The creation of this new specialty would help patients and health care professionals to make more informed choices about how increasing amounts of health data and information can or should inform health care.

**H**ealth care is increasingly data driven.<sup>1,2</sup> More and more domains of people’s lives are “datafied,” meaning

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The authors have informed the journal that they agree that Alena Buyx and Barbara Prainsack have completed the intellectual and other work typical of the senior author.

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that increasing ranges and amounts of information about them are rendered, at least in principle, usable for health care purposes. This is quickly changing the face of clinical practice.<sup>3–5</sup> Health data are now also generated outside of clinical settings, via direct-to-consumer testing, online platforms, apps, and wearables.<sup>6,7</sup> These developments are fueled by the idea that data-rich medicine will lead to better, more personalized health care.<sup>8,9</sup> However, they have also engendered new challenges, including that health professionals often lack the time and training to guide patients through the growing medical “data jungle.” We sketch some of these challenges through the following vignette.

Ana is a patient with a degenerative disease. Active on an online health platform, Ana shares her lab analyses and symptoms regularly with the online community. Upon learning of a new experimental drug study that a company is recruiting patients for, Ana puts together a file with preliminary trial results and a few years of her own data on symptoms, diet, and functional changes that she has collected through various trackers and health apps. She brings the file to her doctor hoping that she may be eligible for the experimental treatment, and asks if she should participate. Her doctor is unable to assess the relevance of Ana’s various patient data or the

experimental study during the short office visit; the doctor is also concerned that the information on the study comes from a source she is not familiar with from her own practice. She has little time to spend with the data file, research the experimental study protocol, or scrutinize the commercial testing methodology. The doctor sends Ana away with the vague promise to discuss the trial during her next visit. Ana leaves, frustrated and confused; the doctor also feels she did not provide sufficient guidance for her patient. What resources do Ana and her doctor have for navigating this situation? How can clinicians and patients make sense of the abundance of unvalidated data from divergent sources, so that patients like Ana may make well-informed decisions?

When devising treatment plans, medical professionals and their patients often find that diverse sets of data, including electronic health records (EHRs), clinical and lifestyle information, genetic testing, drug trials, and biobanks, are potentially relevant for decision making. Moreover, while information used to be seen as flowing from professional experts to patients, institutions and operational procedures must increasingly accommodate information that flows the other way: from patients to their doctors, or from companies to patients and then to clinical professionals.<sup>10</sup> Although we

expect that artificial intelligence (AI) applications such as deep learning and big data analysis will help with data interpretation in the clinic, the task of interpretation cannot be devolved to machines entirely; meaning-making will always require human minds, hearts, and hands, and patients will continue to require support in navigating data decisions. In light of this, it is clear that the time has come to devise a new approach suited to the changing realities of medicine and data. In this article, we offer a bold proposal—namely, the development of a new specialty, initially integrated within academic medicine, to make data actionable for both clinicians and patients in meaningful ways: the creation of a graduate-level degree in health information counseling.

### Challenges Brought by Big Data in the Clinic

Digital health tools are at the heart of visions and practices of data-driven medicine. A glance at an app store shows over 165,000 health-related apps and counting. By 2022, an estimated 430 million digital devices will be produced each year, each creating its own cacophony of data points. Mobilizing the growing capacities of smartphones and wearables, individuals can now generate immense quantities of real-time biometric data about themselves. Some add-ons to smartphones go beyond tracking steps or daily hydration to diagnose, for instance, a heart arrhythmia<sup>11</sup> or an ear infection,<sup>12</sup> or to conduct an ultrasound.<sup>13</sup> Such diagnostic and screening technologies are increasingly moving into personal spheres outside of professional supervision. Although the analytic and clinical validity and utility, as well as the quality, of some of these data are not clear, they are of growing interest to many patients who expect engagement with these data from their health care providers.<sup>6,14</sup>

While the great problem-solving capacities of big data dominate debates in the public domain,<sup>8,15</sup> in the clinic, the increasing availability of health data currently poses as much of a problem as a solution. Information overload can affect patients and doctors alike.<sup>16,17</sup> For patients, judging the quality and understanding the validity of unstructured, possibly health-relevant information is difficult and can lead to

misinformation, uncertainty, and even anxiety over real or misunderstood health risks.<sup>18</sup> Moreover, new types of mistrust within doctor–patient relationships have been documented and partly blamed on more—yet often unreliable—health information from sources outside of traditional clinical realms.<sup>19–21</sup>

For many patients, the empowering possibilities presented by such abundant “information” also pose newfound challenges, such as how to make sense of the results of genetic testing purchased online, or how to decide what to do with an odd heart arrhythmia diagnosed on their smartphone.<sup>11</sup>

The use of big data methods and epistemologies raises concerns that are central to established ethical considerations of clinical interest.<sup>22</sup> Ensuring nonmaleficence is one principle that is challenged by data-related confusion and anxiety in patients, as well as by self-medication based on inaccurate or misunderstood data. Research conducted through online platforms often has methodological limitations, including highly selective samples or inadequate data analysis. There are additional concerns surrounding the protection of patients’ best interests and making sure that patients can give meaningful consent. The difficulties of interpreting unstructured data add another layer of complexity for clinicians trying to decide which course of action would best meet their duty of beneficence and enable the best possible care for patients. Patient autonomy, important for making well-informed decisions, can be compromised by unnecessary tests and procedures that are based on unclear data or misinterpretations of unstructured data. In particular, in times of increasingly “wish-fulfilling medicine,”<sup>23</sup> direct-to-consumer or self-initiated testing could pose problems regarding the efficient and fair use of public health and medical resources, such as in cases where patients receive a misleading diagnosis online and then request further, possibly unnecessary or duplicate, testing from their doctors.<sup>24</sup>

In light of these practical, clinical, and ethical challenges, the time has come to consider a new medical specialty dedicated to rendering diverse individualized and population-level data meaningful for patients and health care providers. Building on its important

role within related fields like health information technology<sup>25</sup> and existing synergies in teaching, research, and service, academic medicine is well poised to take on the challenges associated with the integration, utility, and trust concerns entangled in this watershed moment.<sup>2,6</sup>

### How to Best Navigate Novel and Unvalidated Sources of Health Data?

Let’s return to Ana’s case: Imagine if her physician had been specifically trained in data science and interpretation, and was up-to-date with the newest developments in the field of digital medicine and big data. With such training, Ana’s doctor could assess the sources from which Ana had been collecting her own data, assist her in interpreting any novel and unvalidated sources, and evaluate the study protocol for the experimental study. However, at present, few in the current health care team are well positioned to offer discerning interpretations of diverse, unstructured data to inform clinical decision making in the way described. Regardless, we—as patients and as a society—continue to rely on doctors to fill this gap in evaluating new health data.

Echoing older debates on decision analysis consultations for clinical challenges,<sup>26</sup> there have been numerous calls for more training of doctors in the ethical concerns surrounding the communication of genetic data and related health risks to patients,<sup>27</sup> for counseling patients about the advantages and pitfalls of online or commercial sources of health information,<sup>18</sup> for using big data as a pedagogical tool to improve physician training,<sup>28</sup> and for addressing the growing relevance of AI computational systems for clinical practice.<sup>5</sup> At the same time, expectations and clinical tasks have become increasingly complicated, as a result of information overload, the rapid pace of technology, and expanding conceptual frameworks in medical care.<sup>29</sup> Physicians are already overstretched, and under considerable professional stress.<sup>30–32</sup> Lack of time to speak with patients remains a persistent concern.<sup>33</sup> In sum, there are many compelling reasons why we cannot simply “add” big data concerns to the existing workload of doctors.<sup>34</sup>

The integration of emerging data science concerns into medical and other health

professional curricula has been slow,<sup>35</sup> and for good reason. In view of the speed of medical innovation and knowledge increase, and against a background of a growing burden of illness and rising health care costs,<sup>36,37</sup> mastering the “core” skills and tasks that modern medicine demands of health professionals is already time-consuming and demanding. Others have shown that new generations of doctors do not feel adequately prepared for their work<sup>38,39</sup>; specifically, medical students have expressed feelings of unpreparedness in their ability to apply the subjects of big data, such as in genomics, to clinical care.<sup>40</sup> For instance, the transition to EHRs has required integrating new forms of training into medical curricula, including calls that EHR documentation and management skills be assessed along with clinical competencies.<sup>41</sup> This work points to other critical data skills gaps for the next generation of medical professionals, such as the interpretation of observational material, surveys, and epidemiological data sets.<sup>42</sup> Meeting the challenges of big data in medicine requires new doctors to interact across disciplinary boundaries in unprecedented ways, working with specialists across biostatistics, computational statistics, econometrics, and qualitative research<sup>42</sup> as well as with patients and family members in novel ways. (Patient-reported outcome measures and patient-reported experience measures are two examples of patient-centered and participatory instruments that play an increasingly important role in health care.) They also need to learn to interpret data contextually to account for data limitations in the application to clinical practice.

### **Implications for the Design of Academic Medicine Curricula: Health Information Counselors**

In light of these challenges, we propose a disciplinary-level approach to addressing the challenges of integrating data science in medicine: a new profession, the health information counselor (HIC), to be initially incorporated into the field of academic medicine and later opened to other specialties. Imagine that Ana could meet with a specialist, referred by her physician, who has specific training in health information counseling. The HIC would have broad knowledge of various kinds of health data and data quality evaluation techniques, as

well as analytic skills in statistics and data interpretation. She or he would have been trained in interpersonal communication, health management, insurance systems, and medico-legal aspects of data privacy, and would know enough about clinical medicine to advise on the relevance of any kind of data for prevention, diagnosis, and treatment. Trained broadly, with time and applied experience, practicing HICs would become specialists in a particular domain, and each would know when to refer to a specialist on a matter beyond his or her expertise. Drawing on this background, the HIC could assist Ana in understanding the emerging results from the drug trial, comparing her case with peer-reviewed studies, assessing her suitability for the trial, and considering her options in pursuing a conservative versus experimental therapy. Ana could take her reflections from these meetings back to her doctor, who could also consult with the HIC, and together they could devise a plan of action. The creation and implementation of this new specialty would enable patients to make educated, truly autonomous choices about how these novel forms of health data can inform their personal care decisions.

One of the strengths of the HICs would be their ability to translate the complex language of data into intelligible and actionable information for both patients and physicians. Acting akin to an expert consultation in a clinical specialty, they would offer their professional assessment regarding all issues of patient data interpretation to treating physicians, and oversee many patients as part of their caseload. As part of existing delivery organizations and the health care team, an HIC could be integrated into “Ask the expert” programs in hospitals. Or, in multispecialty group practices, the chief medical officer who provides guidance and seeks out the latest medical findings could be a physician with HIC training. This would allow doctors to use HIC assessments when advising patients on decisions regarding their care, thus freeing up valuable physician time for conversation and clinical examination. Patients, in turn, could consult with an HIC regarding questions they have about health-relevant data, avoiding unnecessary doctor visits and medical interventions, anxiety, and wasted time. The addition of the HIC to the panel of

health professionals could also contribute to the reduction of mistakes, providing a critical resource to assist doctors in staying fully informed about novel tests, research studies, and data programs. The creation of a cadre of skilled HICs would advance the clinical applicability of big data in an ethical, and equitable, fashion.

We envision health information counseling operating as a clinical consultancy, with the ability to interface between patients and physicians, and provide essential patient support services. There are several germane fields in relation to which we wish to situate HIC. Clinical informatics, as a medical specialty for physicians, has been proposed as one model to improve data analysis, visualization, and decision support of health information technologies.<sup>43</sup> The HIC would complement clinical informatics, providing an intermediary who would do the translation work needed to actualize data-driven medicine. HICs would provide counseling both for patients with varying degrees of savvy faced with data-related decisions, and for physicians without the time, knowledge, or resources to take on the demands of integrating big data in a meaningful way into their clinical practice.

Although similar in format, the purview of the HIC would be broader than that of a genetic counselor, as HICs would be prepared to help patients evaluate the reliability of a commercially available test, assess treatment options, or compare information from sources online with their physician’s counsel on questions that are not only of a genetic nature. HICs would also consult on the ethical dimensions and cost-effectiveness of collecting and using data as well as on the utility of different types of data-generating interventions such as health apps or genetic testing, and would provide advice for their use. In this capacity, an HIC could help to protect against overdiagnosis and overtreatment.<sup>44</sup> Akin in other ways to a patient navigator,<sup>45</sup> the HIC would help patients to find their way through the health care system and make informed decisions about their care. The support offered by patient navigators has been shown to reduce health disparities<sup>46</sup>; in a similar vein, the role of an HIC could help to make the potential benefits of big data accessible for a broader range of



patients. However, HICs would be skilled professionals with extensive mastery of technical and clinical skills far beyond those of a patient navigator. A degree as an HIC would need to be regulated and meet specific standards of competency. To the best of our knowledge, no dedicated program or curriculum for HICs exists as a novel type of health professional.

One of the principal challenges will be a viable business model. HICs could help to reduce both harm and cost by helping to prevent overdiagnosis and test duplication. Similar to patient navigators, who were found to “pay for themselves” through the gains made by improved care coordination,<sup>47</sup> it is possible that institutional buy-in could be generated if these cost reductions are demonstrated. Accordingly, HICs would be integrated into existing delivery organizations, as employees of hospitals, doctors’ clinics, or patient and accountable care organizations. Following the model used in genetic counseling, some insurance providers could cover HIC services if referred by the patient’s physician. Billing codes and a revenue stream would need to be established so that HICs could be reimbursed. In the transition from fee-for-service to value-based reimbursements, HICs could help to identify treatment options that are valuable for individual patients, thereby helping to reduce low-value interventions and cost. Employing HICs would thus be particularly relevant for accountable care organizations and other bodies providing integrated care.

Given the complex skills and competencies necessary for successful health information counseling, an HIC degree would have to be postgraduate, likely at a master’s level. We envision this as a highly interdisciplinary program, situated within, or in close affiliation with, a medical school, and substantively linked to departments of epidemiology, biomedical statistics, genetics/genomics, computer science, science education, social medicine, ethics, and health policy. Students graduating would have competencies in:

- Different types of data relevant to clinical decisions, and the scientific, technical, operational, legal, and ethical challenges in interpreting them;

- A critical understanding of the ideas, technologies, and practices informing precision medicine;
- A systematic understanding of the organization of health care services and provision in a comparative perspective;
- An introduction into computational thinking and data science epistemologies, and advanced skills in statistics and data manipulation;
- Familiarity with counseling techniques;
- Familiarity with the ethical, social, and legal dimensions relevant to health data management and patient privacy; and
- Familiarity with social media analytics.

We believe that HIC training would be particularly suitable for those with degrees in health or natural sciences, or for health professionals, including physicians, who want to focus on data science and health information counseling as part of their professional development.

### Concluding Observations: Benefit Across the Clinical Spectrum

Instead of requiring that all health professionals delivering care develop extensive competency in data analysis, we have argued that the introduction of a specialized profession in medical data science such as the HIC offers a promising way to address the growing clinical challenges associated with big data. It would benefit a range of actors in the health care field. First, patients would benefit from having specialized professional support in making deliberate decisions about which kinds, if any, of health information they would like to collect, and how to evaluate available services, including commercial sources. Second, physicians would gain a new resource in navigating a rapidly changing field of molecular, genetic, lifestyle, and digital data. The possibility to consult a professional dedicated to evaluating the utility of specific tests and data sets would free up time to focus on patient needs, as well as for conversation and examination. Third, health insurance providers would likely benefit from more effective and informed data use, more targeted diagnosis, and the avoidance of unnecessary tests and procedures

following unclear or misinterpreted data.<sup>48</sup> This includes preventing overdiagnosis and overtreatment by also being mindful of what patients do not want, and encouraging personalization in treatment as well as nontreatment decisions. The HIC profession could help to reduce errors and improve coordination of care in data-driven medicine, particularly against the backdrop of a shift toward value-based and integrated health care. Introducing HICs could thus arguably help reduce health care costs. Additionally, at least for HICs who are not MDs, they would provide a valuable service that is likely less expensive than a physician consultation. This is of increasing importance given findings that rising costs of health care in the United States could undermine the role of big data.<sup>1</sup> Finally, by making the HIC part of the health care team, the benefits and nuances of big data would be made more widely available to all involved.

Data-driven medicine offers many opportunities for the delivery of better care. For some, these developments are a welcome expression of the potential for data-rich medicine. For others, the new computational possibilities are also likely to exacerbate overdiagnosis and increase costs. In this context, leaving the problem of how to personalize health information unaddressed is not feasible. Neither is simply adding the metaskills of managing and evaluating health information to the existing tasks of physicians, without establishing a new profession. To be sure, building up and introducing new degrees and curricula are uphill organizational and political battles. In particular, established health professionals may be reluctant to cede agency and control of a health-related domain, and new challenges would emerge, including the structural assimilation of this profession into care teams. The meaningful integration of data science into the clinic is quickly turning into one of the defining challenges of 21st-century medicine. We call on our colleagues in academic medicine and medical education, as well as clinical medicine and health policy, to start considering new ways to address the growing problems that the digital data deluge poses for doctors and patients. It is time to share the burden to make the gains brought by digital innovation and medical research actionable for all involved.

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